CDC's State-Based Birth Defects Tracking

"Thanks to the state birth defects registry, I learned about how important it is to take a multi-vitamin with folic acid, stop drinking and smoking, and talk to my doctor about my health concerns before and during pregnancy."

-Mom from Florida

"We didn't really know where to turn, what to do, you know, we had some ideas and it was nice that we had the involvement of the public health department to get us started in the right direction."

-Father of a child with Down syndrome, about the value of referral to an early intervention program.

Understanding Birth Defects

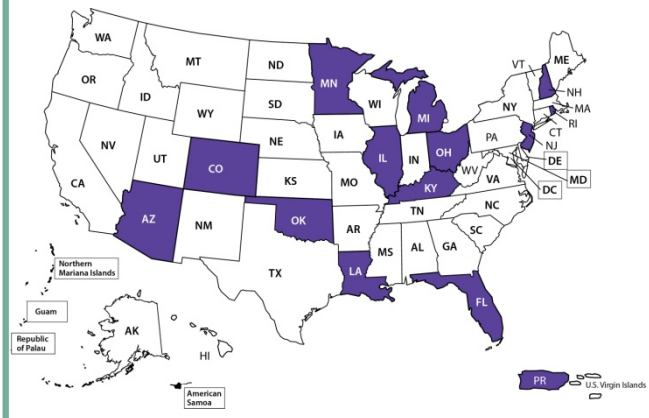
- **One in every 33 babies in the U.S. is born with a birth defect.**
- **Birth defects are a leading cause of infant mortality in the U.S., accounting for 1 in 5 infant deaths.**
- **In the U.S. each year, the total costs for hospital care of children with birth defects exceed $2.6 billion.**
- **Babies who survive and live with birth defects are at increased risk for many lifelong physical, cognitive, and social challenges.**

Identifying Birth Defects

The Centers for Disease Control and Prevention (CDC) funds population-based birth defects tracking systems in Arizona, Colorado, Florida, Illinois, Kentucky, Louisiana, Michigan, Minnesota, New Hampshire, New Jersey, Ohio, Oklahoma, Puerto Rico and Rhode Island. These programs track babies with birth defects and use the data collected for prevention and referral activities.

Birth defects tracking systems are vital for monitoring and detecting trends, providing information to find causes of birth defects, and planning and measuring the effects of activities aimed at preventing birth defects. Additionally, identifying birth defects at a state level strengthens public health officials' ability to estimate prevalence and evaluate risk factors that are most important in their community.

CDC-funded Birth Defects Tracking Systems, 2011



Improving the Lives of Children with Birth Defects

Babies who have birth defects often need special care and interventions to live longer, healthier lives. Birth defects tracking systems provide one way to identify and refer children for services they need as early as possible. Early intervention is vital to improving outcomes for these babies. Knowing how many babies have birth defects helps policy makers allocate resources and services to help affected children and their families.

Preventing Future Birth Defects

Tracking where and when birth defects occur and who they affect gives us important clues about preventing birth defects. Analyzing the data allows us to identify factors that can increase or decrease the risk for birth defects and identify community or environmental concerns that need more study. State-based birth defects tracking programs provide important insights into our continued efforts to prevent birth defects and support families affected by them.

Examples of Birth Defect Tracking Activities

- In **Colorado**, data are used to refer babies with birth defects for early intervention services. This program is also measuring the effectiveness of referral efforts and the impact that referrals have on affected children and families.
- In **Florida**, data are shared throughout the state to promote birth defects prevention. Program staff works with state and local groups to promote intake of folic acid before pregnancy and to reduce high-risk factors such as smoking and alcohol use, during pregnancy.

Continuing and Expanding Birth Defects Tracking

There is still much to learn about birth defects. Broadening the scope of birth defects tracking will further our understanding of the causes and risk factors for birth defects. Improved tracking would allow for better estimates of prevalence, types of health services needed, and costs of such services. CDC's ongoing and future state-based birth defects priorities include:

- Enhancing state birth defects tracking systems
- Monitoring the occurrence of neural tube defects to assess the continued impact of folic acid fortification
- Supporting the National Birth Defects Prevention Network activities, including annual publication of state data and development of birth defects tracking standards
- Conducting regional birth defects meetings
- Providing technical assistance to states
- Developing an evaluation framework and tools to improve the utility of these systems

National Center on Birth Defects and Developmental Disabilities:
For more information please contact Centers for Disease Control and Prevention
1600 Clifton Road NE, Atlanta, GA 30333
Telephone: 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-63548
Email: cdcinfo@cdc.gov Web: www.cdc.gov